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Improving Patient-Centered Communication of the Borderline Personality Disorder Diagnosis

Sandra H. Sulzer Dr.,

University of Wisconsin-Madison

Elizabeth Meunchow Ms.,

National Alliance on Mental Illness, Minnesota

Annabelle Potvin Ms.,

National Alliance on Mental Illness, Wisconsin

Jessica Harris Ms., and

University of North Carolina at Chapel Hill

Grant Gigot Mr.

University of Wisconsin-Madison

Abstract

Background—Borderline Personality Disorder (BPD) has historically been difficult to diagnose, and laden with stigma, leading to a variety of clinical responses to patients who present with symptoms.

Aims—1. To understand how clinicians communicate the diagnosis of BPD with patients. 2. To compare these practices with patient communication preferences. 3. To use patient preferences to evaluate clinician practices.

Methods—Semi-structured interviews with mental health care providers and experts (n=32) were compared with patients (n=10) and patient primary written accounts (n=22). Grounded theory was used to explore causal pathways between clinical practice and patient responses.

Results—The majority of clinicians sampled did not actively share the BPD diagnosis with their patients, even when they felt it was the most appropriate diagnosis. The majority of patients wanted to be told that they had the disorder, as well as have their providers discuss the stigma they would face. Patients who later discovered that their diagnosis had been withheld consistently left treatment.

Conclusions—Clinicians believed that by not using the BPD label they were acknowledging or sidestepping the stigma of the condition. However, from the perspective of patients, open communication was essential for maintaining a therapeutic relationship.

Corresponding Author: Sandra H. Sulzer. 1100 Delaplaine Ct, Madison, WI 53715 (t) 608-263-4550 shsulzer@wisc.edu.

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Introduction

Borderline Personality Disorder (BPD) is difficult to diagnose. One medical school professor stated, simply, “the borderline patient [is] hard to describe, but if he/she were sitting in one of our offices, we would instantly know” (Becker, 1997, p. xiii). The difficulty describing these patients may be linked to the complexity of the diagnostic criteria.

To receive the diagnosis, under the DSM IV (which was in use during data collection) a patient needed to meet five of nine criteria including self-harming behavior, a history of unstable and intense personal relationships and dissociative episodes, or breaks with reality. There are more than 180 possible combinations of criteria that could qualify someone to receive the diagnosis. In DSM 5, minor changes to the language of criteria were implemented, not affecting heterogeneity.

In addition to its diagnostic complexity, BPD is arguably one of the most stigmatized conditions in the mental health field (see for discussion: Koekkoek, Meijel & Hutschemalkers 2006, Nehls 1998, Treloar 2009, Hyde 2010, and Rogers & Dunne 2011). Nehls (2000:62) states “there may be no psychiatric diagnosis laden with more stereotypes and stigma than borderline personality disorder.” Clinicians perceive patients with BPD as being manipulative and difficult (Nehls 1998). Recent ethnographic work has demonstrated that nurses show less sympathy for them than patients with other mental illnesses (Treloar 2009; Rogers & Dunne 2011). Patients are often described as untreatable or “not really sick,” (which is a paradoxical conundrum since one implies severe sickness and the other dismisses the possibility). And yet, carefully controlled trials demonstrate they are just as treatable as patients with Major Depressive Disorder (the most common diagnosis in the US) with access to effective evidence-based treatment such as Dialectical Behavioral Therapy (DBT) (Gunderson et al., 2011; Linehan et al., 2006; Lieb, Zanarini & Schnahl, 2004).

Due to the stigma attached to the BPD diagnosis and the complexity of criteria, clinicians may couch their communication with patients regarding the diagnosis. Since there is little empirical evidence of how clinicians make decisions about how or when to communicate this diagnosis with patients, nor are there substantial patient reports available, a qualitative study was best-suited to understanding the variety of practices in the field. The patient responses in this study aim to provide a practical feedback loop for clinicians.

The purpose of this research was to conduct an exploratory, grounded theory study that compared clinician communication practices with patient experiences. Specifically, the goal of this research was to determine the effectiveness of current communication strategies surrounding sharing the diagnosis of Borderline Personality Disorder with patients.

Methods

Thirty-two patient accounts and 32 clinician accounts were used as data (n=64). Of these, 10 patients were interviewed in person. Interviews were triangulated with 22 written first-hand patient accounts: 6 published memoirs and 16 patient stories from online postings. Triangulation in qualitative data collection is an important way to ensure the validity of findings (Guion, Diehl & McDonald 2011). There is a common misconception that sources

used for triangulation should be generalizable and consistent (see Patton 2002). However, data sources with different strengths and weaknesses can be used to challenge or integrate theories, increasing the utility of findings and the validity of conclusions (Guion, Diehl & McDonald 2011). Thirty-two clinicians were interviewed, 22 before the release of DSM-5, and 10 in the months immediately following. Clinicians and patients were both recruited using national purposive sampling. Becker & Lamb (1994) found that clinician diagnostic practices related to BPD varied by both clinical training and the sex of the provider. Accordingly, clinicians were initially recruited to fill a sampling frame of male and female providers, with different professional training (psychiatry, psychology, social work). Clinicians were subsequently recruited using snowball sampling, with no more than two additional clinicians interviewed from any one referral source^a. Purposive sampling was then used to recruit clinicians who were likely to illuminate views not already well-represented in interview data. Following the recommendation of Watters & Biernacki (1989), persons diagnosed with BPD were recruited outside of clinic settings, using flyers in public places. This strategy was used primarily to increase the likelihood of candor with the interviewer, and to increase the likelihood of encountering patients beyond those enrolled in care, happy with care, or comfortable speaking with someone who appeared to be affiliated with a clinic. Given the stigma of the condition within the mental health field, outside recruitment aided all of these aims. Sampling ended when saturation was reached. This is the gold standard for qualitative data collection in developing grounded theory (Charmaz 2006). If nothing new is learned across several interviews, the sample is considered “saturated” or as informative as it is likely to become. This does not demonstrate that the data is generalizable to the population, but it does suggest that the most dominant themes across a population are represented.

All subjects were adults, though their mean age is unknown as 40% of the sample included unobtrusive data collection. Interview participants ranged from approximately twenty years old to their mid-seventies. Among the patient sample, 7 of the 10 interviewees were women. Among the clinician sample, 22 of 32 were women. Among textual sources, the possibility of using anonymous handles on the Internet prevented a final count of participants' gender.

Clinicians included 8 psychiatrists, 16 psychologists, 6 Licensed Clinical Social Workers and 2 BPD activists that both had graduate-level scientific training. They ranged in expertise from clinical residency to nearing retirement, and had roles ranging from emergency room intake to private practice to directors of major psychiatric centers.

Interviews ranged in length from 30 minutes to three hours, averaging one hour per respondent. Clinician interviews were conducted over the phone or in-person, and patient interviews were all conducted in-person. Respondents came from eleven states: Wisconsin, New York, Maryland, New Jersey, North Carolina, Mississippi, Pennsylvania, Alaska, Illinois, Texas and Minnesota. Interviews were semi-structured and focused on the diagnostic encounter. For clinicians this included tracking how they would ordinarily make a

^aPatients were given the opportunity to refer others to the study. However, all participants stated they did not have anyone in their social network who had also been diagnosed with BPD. Therefore, snowball sampling was not possible with this group.

diagnosis of Borderline Personality Disorder and for patients this included asking how they learned of their diagnosis. Self-diagnosed patients were not admitted to the study.

The data were collected from 2011–2013. This study was approved by the University of Wisconsin Madison Institutional Review Board (IRB), and subsequently by the University of North Carolina, Chapel Hill IRB. All interview participants voluntarily gave written informed consent after the study had been fully explained to them. Textual accounts were reviewed by the Wisconsin IRB and granted an exemption of informed consent as non-human subjects research.

Analysis

Analysis followed a Constructivist Grounded Theory model (Charmaz, 2006), which builds theory in an abductive process. Constructivist Grounded Theory emerges from the tradition of Glaser & Strauss (1967), but draws most particularly from Strauss' interpretation of Grounded Theory Practice (Strauss & Corbin, 1997). This method emphasizes constructing theory through an iterative coding process which identifies themes, involves ongoing data collection and an integrated memo-writing process. Interviews were fully transcribed and all data was coded qualitatively for themes. For this particular study, information about how diagnosis was performed and conceptualized was the main focus in clinician data. Within patient data, experiences of receiving a diagnosis and perceptions regarding the communication process were coded. Each variation in practice or experience was grouped into categories to clarify patterns in diagnostic processes. For example, clinicians were divided into 1) those who always informed the patient of the BPD diagnosis, and 2) those who sometimes, or never did. Within those categories, clinicians were grouped based on their rationale for their decisions. This helped to accentuate clear patterns in the day-to-day diagnostic process of a variety of practitioners. The data was coded in N*Vivo, a qualitative software program. Codes were compared through a constant comparative method within the coding process. This involves iterative coding where earlier and later data are compared within and against themselves for internal consistency (Glaser & Strauss 1967). This is particularly important in substantive areas where there has not been sufficient past research from which to meaningfully formulate hypotheses, and theory is being driven by findings from a carefully analyzed dataset.

Results

A: Clinician Diagnosis Strategies

Strategy 1a: Withhold BPD in favor of Axis I Diagnosis—Clinicians used a variety of tactics to communicate their patients' mental health conditions, generally without directly giving the diagnosis of Borderline Personality Disorder. The primary strategy was exclusively citing an Axis I disorder. For example, clinicians often chose to discuss comorbid mood disorders like depression and anxiety without disclosing the borderline diagnosis. Providers also commonly used Post Traumatic Stress Disorder as an alternate label, which some providers described as a less “blaming” way to discuss BPD symptoms with patients.

Strategy 1b: Withhold BPD in favor of Euphemistic Diagnosis—A second strategy clinicians employed involved the use of euphemisms such as “Cluster B Symptoms,” “Borderline Traits” or “Difficulty Regulating Emotions.” These expressions were used in place of a diagnosis when explaining to the patient that they had a mental health condition. Such diagnoses are not APA recognized and do not appear in the DSM-IV or DSM-5. Some providers alternated between these first two practices (Axis I Diagnosis or Euphemisms), or only occasionally disclosed the actual diagnosis. As a result, providers did not fall into mutually exclusive categories, making rates of communication strategies impossible to calculate.

Clinicians justified both of the non-disclosure practices described above by explaining that patients would be dissatisfied, displeased, dependent on or resistant to the diagnosis of a Borderline Personality Disorder, while also feeling pressured to provide some kind of name for their suffering. Furthermore, every clinician in my sample acknowledged the particular stigma of this label and worried that the diagnosis would do more harm than good. Clinicians disagreed about the extent to which patients perceived or understood the stigma of the disorder upon initial diagnosis. However, they largely predicted that patients would receive the diagnosis negatively or reject the label due to the stigma linked to it. Providers justified both of the above two strategies as a means to protect patients from feelings of shame and stigma, while also advancing their likelihood of healing through treatment.

Strikingly, clinicians anticipated patients would be aware of the stigma of the label, while also generally agreeing that the general public was unlikely to be aware of the condition. In other words, the stigma of the condition largely seems to be present among mental health service providers, not in the everyday lives of most patients. While the implications of this are beyond the scope of the findings of this article, this would suggest that the stigma clinicians are concerned about is to some extent manufactured within their professions.

Strategy 2: Full Disclosure—Only three providers (9%^b) *always* told their patients if they thought they had Borderline Personality Disorder. These providers sometimes also discussed Axis I co-morbidities, but not in lieu of the BPD diagnosis. They did not use euphemisms. This third strategy remained mutually exclusive of the other two. Clinicians justified this strategy based on the belief that disclosure of the diagnosis of BPD was an indisputable component of informed consent, and therefore a required part of their professional duties.

B: Patient Reactions to Clinical Strategies

Patients recounted their experiences of discovering their diagnosis. Many did not learn that they had been diagnosed with BPD directly from their clinician, but rather from requesting

^bVery few percentages are included in this article intentionally. Based on grounded theory, this sample is not intended to be generalizable, and furthermore, purposive sampling removes the meaningfulness of relative percentages. As sampling continues, the researcher chooses new data based on its likelihood to illuminate themes that are not well represented in the current data. In this way, we gain more sufficient data on less common themes. At the same time, we collect less data on common themes because there is no reason to continue to collect stories nearly identical to those already in the dataset once saturation has been reached. This percentage was included because despite efforts to illuminate all themes, only three providers actively, and always, told patients of their diagnosis, suggesting that this is likely to be reflective of the broader field. However, this percentage should not be understood as an indication of absolute prevalence, but rather as an important piece of data within the sample.

medical files or when a subsequent provider let slip that the diagnosis had been listed in their records long before. A small minority of patients did learn their diagnosis directly from the provider, though often it was not their first provider. These patient experiences were consistent with the communication strategies described above by clinicians: most did not always disclose, a few did.

Most clinicians had agreed that telling a patient they had Borderline Personality Disorder would elicit a negative emotional response or possible rejection of the diagnosis, but this was not supported by the data. However, all 32 patients in the sample agreed they met the criteria for BPD at the time of sampling. A typical response: “My eyes widen as they move down the list [of criteria]. I meet all nine” (Johnson, 2010, p. 138). 100% acceptance may at least partly be an artifact of sampling: it is unlikely that someone who disagreed with the diagnosis would write a memoir, agree to be interviewed, or post in an online community.

Two patients experienced a delay in accepting the diagnosis, and one had an ongoing negative emotional reaction. This patient said “I know for some people, having a diagnosis and being able to read up on it might be a blessing, but I’ve started to slip into a bit of depression over what seems like pages of hopelessness.” In this case, clinician fears of the impact of stigma were validated. However, this patient still went on to seek further help, suggesting that stigma was not a barrier to continuing treatment.

Meanwhile, and unexpected to clinicians, the vast majority of patients in the sample expressed relief and feeling a sense of belonging, “I’d say to some degree there was like peace of mind that I fit somewhere,” as well as understanding: “It finally makes sense why I’ve been the way I’ve been for so many years.” As one patient shared, “I’ve had it for at least 20 years; it’s a relief to finally be diagnosed.” Many viewed the diagnosis as a crucial step toward getting effective treatment and information, “I really want the diagnosis, and I really want something that I can help myself with.” The diagnosis was viewed as a necessary component to proceeding with effective treatment.

Two additional trends were not anticipated by clinicians. First, some patients responded critically, not by disagreeing with whether or not they met the criteria, but rather by questioning the meaning of the criteria. These were literate critiques of psychiatry that clinicians too debate (Phillips et al 2012a, Phillips et al 2012b, Phillips et al 2012c, Phillips et al 2012d). “To categorize someone in great distress as having a ‘disordered personality’ is fundamentally stigmatizing and flawed in concept. I no longer fulfill the criteria for borderline personality disorder (BPD), yet my personality hasn’t changed!” Similarly, Susanna Kaysen, a patient famous for her memoir, *Girl, Interrupted*, debates the symptomology of lack of self-image: “My self-image was not unstable. I saw myself, quite correctly, as unfit for the educational and social systems. But my parents and teachers did not share my self-image. Their image of me was unstable, since it was out of kilter with reality and based on their needs and wishes,” (1993, p. 155). These critiques were insightful, but not in disagreement about whether or not the patient met criteria. Instead, these responses included patients asking questions about the meaning of the criteria, while continuing to follow-up with care.

Second, patients told they had euphemistic or Axis I labels suffered an iatrogenic reaction clinicians did not anticipate: confusion. One patient thought she had bipolar disorder for more than a decade, having never received an explanation of what BPD actually stood for. Many confused reactions came from patients who discovered their diagnosis by means other than direct communication between clinician and patient. These cases include a patient who found out via a treatment plan document, another who hired a lawyer to demand his charts, and one patient who left her therapist after she found out he had been hiding the BPD diagnosis from her. Euphemistic labels were even more problematic: one patient posted online about her diagnosis of “Borderline Features,” speculating about whether or not she might really have BPD, and feeling uncertain about what kind of treatments were available to someone who only had “features.” The results of the lack of direct communication limited patients’ ability to be agents in their own care and to maintain ongoing therapeutic relationships with providers.

C. Implications of Communication Practices

Whether a clinician only discloses an Axis I label or uses a euphemism, this prevents a patient from fully understanding their condition in the terms the clinician understands it. A patient who receives a euphemistic label cannot look up their diagnosis in the DSM, they cannot research treatment options, and they are also denied an opportunity to question or name their condition, which may be important to their identity (Bury, 1982; Charmaz, 1983). One patient summarized her experience after watching clinicians silently write in her chart: “It’s like that scene in *Girl, Interrupted* where she goes and looks up her own medical file because they won’t tell her. It’s obviously not that same situation, but I just wish they’d be really up front with me.” Unbeknownst to this patient, she was more or less describing the same situation: *Girl, Interrupted* was the story of a young woman receiving mental health care for Borderline Personality Disorder nearly half a century earlier. This aspect of clinical practice had not meaningfully changed in the interim.

If clinician assumptions about the stigma of the diagnosis being a barrier to treatment were valid, then we would expect that most patients who received the label would react negatively to the diagnosis, reject it for some period of time, or find that their treatment was inhibited. We would not expect most patients to feel relief, to agree with the diagnosis or to find it therapeutic. However, that is exactly the kind of positive reaction we found in patients’ responses to their diagnosis. As one patient recommended: “I think the more sympathetic that the clinician can be, and maybe can say ‘well you know I really want to help you and you know, you could feel better if we both are open in discussing this.’”

Discussion

While this research is conducted with a meta-view of clinical activity and cannot replace the individual discretion of a clinician in any particular case, the larger message is clear. These findings suggest that the best strategy to reduce confusion, appease the desire for a diagnostic label, and promote relief is to use the actual label of BPD. Clinicians are also encouraged to discuss the presence of stigma, and strategies for focusing on effective treatment options rather than stereotypes. Furthermore, to the extent that clinicians agree

that the stigma of BPD is largely situated within the mental health care profession, the answer lies within the culture of care provision, not with the label itself.

The implications of these findings likely echo well beyond this particular diagnosis. There is a historical precedence of withholding stigmatizing diagnoses in a variety of contexts. Cancer diagnoses, for example, as recently as the 1980's in France were often only shared with family members, rather than with the patient (Jutel 2014). The paternalistic belief that patients are not always capable of being full agents in their own treatment is a carry-over from turn-of-the-century medical practice. This perspective had been increasingly contested by literature on the importance of participatory communication between clinicians and patients regarding diagnosis, treatment and medication side effects, among other components of care (see for example, Sleath et al 2014).

Conclusion

Current clinical practices may be well-intentioned, and the stigma of BPD may be very real, however withholding the borderline diagnosis from patients may not be the best way to respond. This practice may increase the apparent “Voldemort” status of a condition rather than yielding more beneficial responses through clear, calm and candid discussion. This is particularly important when we consider that 100% of patients who discovered their diagnosis had been withheld subsequently left treatment with that provider. How many sought treatment elsewhere is unknown, but such a consistent finding suggests other strategies may more effectively combat stigma without jeopardizing patient adherence to treatment. These findings are echoed within the increasing attention to scholarship which addresses the patient experiences of persons diagnosed with BPD (See Black, Murray & Thornicroft 2014; Dudas 2014; Sulzer 2014). This may not be a representative sample and future research must test the generalizability of these findings, as well as how the implementation of the DSM 5 shifts clinical practices. However, this study offers a clear starting point for improving the diagnostic communication surrounding Borderline Personality Disorder, and demonstrates the need to incorporate patient perspectives into clinical research. The path forward includes more direct dialogues in both the research and clinical settings so that treatment may better reflect the changing and varied needs of this population. Better communication with patients offers the opportunity for a more patient-centered interaction that may improve treatment participation and adherence.

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